Respite Care for people with disability in South Australia

Respite provides families/carers with a temporary break from the responsibilities of caring for a person with disability—a break from routine. Many families regard respite care as the most important source of support in sustaining the family unit.

Respite is also a way the person with disability can have a break from their normal routine. This break may come in various forms such as a holiday, a weekend away or something different to do on a Saturday afternoon. Respite can provide positive outcomes and different experiences, such as the opportunity to develop new contacts, visit different places and encourage a broader range of friendships.

Initially, the benefits of using respite may not be obvious to those involved. It takes time for everyone to adjust, relax and unwind.

Why do families and carers use respite?

As children grow up and develop their own friends and interests they become increasingly independent of their families/carers. Social activities like outings with friends, sleep-overs and camps provide families/carers with naturally occurring breaks.

This is frequently not the case for people with disability where the need for ongoing care can place undue pressure on families/carers. It also means that the person with disability may miss out on social activities and outings.

The main carer is often dependent on family and personal networks to take time out to do many of the things most people take for granted.

Families/carers use respite for a variety of different reasons. If your answer to any of the following questions is "yes", respite may be of benefit to you or your family:

- Would my family member with disability like an afternoon, weekend or block of time doing something different outside the family?
- Do we need a break from each other? Would my family member with disability like a break to do something for him/herself?
- Do I need some time to organise and attend appointments? Do I worry that there may not be anyone to care for my son/daughter if an emergency arises?
- Am I feeling tired and burnt out, badly in need of a holiday or a rest?
- Do I avoid going out because I feel I am imposing on other people to care for my family member?
- Is it important to me to spend quality time with my partner and my other children or would I like to have a break to do something for myself?
What are the different forms of respite available?

As a family’s/carer’s individual respite needs and preferences vary, so does the range of options available. Respite can be for a few hours, a day, overnight or longer and may take place in or out of the family home.

Some families/carers use respite regularly, others use it only occasionally for specific purposes (like going on holiday).

**The main forms of respite**

**Informal support**

The support provided by other family members, friends or neighbours often provides an opportunity for families/carers to have a break from the responsibilities of caring. It allows the person with disability to experience new contacts or different aspects in their life.

Family members, neighbours, friends or people you know through work, church or other social activities can make up your family’s informal support networks.

Informal networks are often available at short notice and can provide opportunities for mutual support.

**In-home respite care**

In-home respite care involves having someone come into the family home and take over the function of the main carer for an arranged period of time.

This service is generally quite flexible and may be used in a variety of ways (for example to provide personal care, support with recreational/leisure activities or to undertake some domestic activities such as preparing a meal while taking care of the person with disability). Some in-home respite programs use volunteers, others employ workers with specific skills and training.

In-home respite programs may be fully funded or require some contribution from the family. Generally there is a restriction on the number of families/carers who can access these programs and the number of hours that are available.

**Host family programs for children**

Host family programs "match" or "link" a family in which there is a child with disability to a host or host family.

The host or host family then takes on a support role for the family by providing care for the child in their own home on a regular, planned basis.

Host family programs are generally licensed by Families SA who set the standards for screening, training and approval of hosts and host families.

A small contribution may be required from families/carers to cover some of the costs associated with the child's care.

The recruitment, screening, and training of hosts and host families is quite a lengthy process and most host schemes have waiting lists.

Some services may provide emergency respite for families/carers accessing the program but this is dependent on the availability of the host or host family.
Respite through recreation
Supported holidays, camps and recreation programs are other respite options that provide both people with disability and their families/carers with positive outcomes.

Centre-based respite
This generally takes the form of a house in the community with staff support. There are usually separate venues for adults and children. Children's venues are licensed by Families SA.

The number of adults or children accessing the venue at any one time and the availability of respite will vary.

Some services offer planned, regular respite to a limited number of families/carers and usually have a waiting list. Other services use an open booking system where those who are first to call in any particular booking period are catered for first (that is, "first come, first served"). Access to these programs is generally more infrequent.

Some services operate up to seven days a week, others only on weekends, school and public holidays.

There may be a limit on the number of respite hours families/carers may use over the period of a year.

There is a cost to families/carers that may vary between services.

Some services can provide an emergency response to people who use the service regularly but this is usually dependent on a vacancy at the time of request.

Mainstream children's services
Most services for children like Family Day Care, childcare centres and after school hours care programs have additional resources and funding to cater for children with disability.

Access to respite through these programs depends on the number of funded places and the availability of care providers with the necessary level of skills and experience.

Fees charged are based on the family income.

Nursing homes and other aged care services
Access to respite beds in these facilities is dependent on age or the level of care a person requires. Eligibility is determined by Aged Care Assessment Teams (ACAT). ACATs cover all of Australia and are based in hospitals or in the local community. Information about the ACAT closest to you is available from Commonwealth Respite and Carelink Centres on 1800 052 222.

Do different respite programs have different eligibility requirements?
Eligibility for disability-specific respite programs is generally determined by guidelines established by the service. Funding may be provided to the program for a specific target group.

Factors like a person's age, the nature of the disability and the level of support required are taken into account. Services vary in the length of time, the process and the amount of information they require to establish eligibility.
How do I access respite?
Referral processes and access procedures will vary between services. Some services accept referrals directly from families/carers, others require that they come from professionals within other human service organisations. Assistance and further information is available from your regional Disability SA office or Commonwealth Respite and Carelink Centres (see below).

How do I know this is the right respite service?
Asking the following questions about the respite program may help to alleviate some of your concerns and assist with choice.

- How are care providers screened? What is the training and level of experience of the care providers?
- Will care providers need additional training to meet the specific needs of your family member?
- How and by whom, are the care providers supervised?
- What happens during the time that the person is receiving services?
- Are there organised activities? What choices are available to your family member while in respite?
- How are meals handled?
- Does the program maintain current information about each person's medical and other needs? Is there a current written care plan?
- What procedures does the program have for emergencies?
- Can families/carers meet and interview the people who care for the person with disability?
- How far ahead of time do families/carers need to call to arrange for services?
- Are families/carers limited to a certain number of hours of service?
- Does the program provide transportation?
- Can the provider take care of brothers and sisters as well?
- What is the cost of services? How is payment arranged?

More information about respite services
Assistance and further information is available from:

- Commonwealth Respite and Carelink Centres give free, confidential information on local support services.
  - Freecall: 1800 052 222 (charges apply from mobile phones and pay phones)
- Disability Information Service on 1300 786 117
- your local disability office.